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"I have the strength to get through this using my past experiences with HIV": findings from a mixed-method survey of health outcomes, service accessibility, and psychosocial wellbeing among people living with HIV during the Covid-19 pandemic

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ABSTRACT

We examined the impact of Covid-19 restrictions on the wellbeing and access to care among people living with HIV (PLWH) in the UK. A cross-sectional anonymous online survey was circulated to PLWH attending care at three HIV services in Sussex. The questionnaire covered key themes: socio-demographic characteristics; changes in physical and mental health; accessibility of essential health services and information; and socio-economic concerns. Free-text qualitative responses were examined through framework analysis. Quantitative data from 653 respondents were available, with a subset of 385 free-text qualitative responses. In terms of mental health, 501 (77.6%) respondents reported feeling more anxious; 464 (71.8%) reported feeling more depressed than usual; and 128 (19.8%) reported having suicidal thoughts since the start of the pandemic. Respondents worried about running out of HIV medicine ($n = 264$, 40.7%); accessing HIV services ($n = 246$, 38.0%) as well as other health services ($n = 408$, 63.0%). Widespread resilience was also noted: 537 (83.3%) of respondents felt that living with HIV had equipped them with the strength to adapt to the Covid-19 pandemic. Findings highlight important gaps between the multifaceted needs of PLWH. Multisectoral collaborations and investments are needed to adequately support PLWH and to build resilience to future shocks within HIV services.

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HIV; Covid-19; pandemic; health outcomes

Introduction

The SARS-CoV-2 pandemic is a global public health crisis posing numerous health, social, and economic challenges. At the time of this writing (December 2020), SARS-CoV-2, the virus responsible for the coronavirus disease 2019 (Covid-19), has spread rapidly around the world and has caused over 63 million infections and 1.5 million deaths(Dandachi et al., 2020). The UK is one of the hardest-hit countries, with more than 58,000 confirmed deaths due to Covid-19 complications (John Hopkins Coronavirus Resource Center., 2020). The Covid-19 pandemic has resulted in multiple prevention strategies, including lockdowns, social distancing, testing and tracing of contacts, and a shift to remote health service provision via digital technologies such as text messaging and phone calls.

The UK is home to 1,03,800 people living with HIV (PLWH), many of whom are aging (39.8% over the age of 50) and have increased healthcare needs due to comorbidities. Both the Covid-19 pandemic and associated prevention measures are likely to affect the health and wellbeing of (PLWH). Similarly, in those individuals that have been living with HIV for many years, it is likely that the Covid-19 pandemic has also triggered memories from the AIDS pandemic, including laws that contribute to blaming, prejudice, and stigmatization, which hampered efforts to control HIV.

The full consequences of SARS-CoV-2 anxieties, lockdown, isolation, and economic instability on PLWH are unknown. The majority of research on the impact of SARS-CoV-2 on PLWH around the world has focused on health and service delivery outcomes

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(Dandachi et al., 2020; Etienne et al., 2020; Gudipati et al., 2020; Jiang et al., 2020; Karmen-Tuohy et al., 2020; Sigel et al., 2020). The impact of the Covid-19 pandemic on the psychosocial wellbeing of PLWH remains understudied, with emerging evidence from China, the US, and Argentina (Guo et al., 2020; Jones et al., 2020; Siewe Fodjo et al., 2020). Given the nascent state of the literature, substantial evidence gaps remain. First, to our knowledge, no UK studies have simultaneously captured health, service delivery, and psychosocial outcomes in a large sample of PLWH. Second, globally, few studies have taken on a mixed-method approach, which is essential for ensuring that findings are grounded in participants' experiences. This study examines the impact of the Covid-19 pandemic on health, service accessibility, and socio-economic wellbeing among PLWH. To our knowledge, this is the largest mixed-method survey focusing on the multifaceted impacts of Covid-19 on PLWH.

Material and methods

Procedures

A cross-sectional, mixed-method, and anonymous survey among PLWH attending care at three HIV services in Sussex, UK, was conducted between 8th of May and the 8th of July 2020. Data was collected using an online GDPR-compliant survey. Potential participants were invited to participate through a web link that was disseminated via text messages sent to all patients that had previously consented to receive text message notifications related to health services. Three HIV services took part: Brighton, East Sussex, and West Sussex, a total $n = 2{,}700$ PLWH (who had consented to text messages). The survey was part of a service evaluation, as such, did not require ethical approval following an assessment using the UK Health Research Authority research decision tool (http://www.hra-decisiontools.org.uk/research/). Participants over the age of 18 who self-identified as living with HIV and provided e-consent were eligible to participate. There were no exclusion criteria.

Survey design

The survey was co-produced between PLWH, HIV clinicians, the Terrence Higgins Trust, and social scientists in virtual meetings which took place throughout April 2020. In addition to basic socio-demographic information, the survey focused on three themes identified in the co-production phase: (1) Changes in physical and mental health; (2) accessibility of essential health services and information; and (3) socio-economic concerns and wellbeing during Covid-19. Questions about patient symptoms or experiences offered response options on a 5-point Likert scale. For example, response options to the question "Since the start of the Covid-19 pandemic, have you been feeling depressed or low in mood more than usual?" Were 1: Not at all; 2: Occasionally; 3: Sometimes; 4: Most of the time; and 5: Always. These were dichotomized to differentiate between those responding "not at all" (for "no" coded as 0) and those responding "occasionally", "sometimes", "most of the time", or "always" (for "yes" coded as 1). In addition to quantitative questions, two free-text comment boxes were included asking participants to "Please use the space below if you want to tell us anything else about how the Covid-19 pandemic has affected you as a person living with HIV" and "What have been your main problems and worries since the start of the Covid-19 pandemic that you haven't managed to find any support for?". The full survey is provided in the supplementary material of this article.

Data analysis

Responses to quantitative questions were analyzed by running frequencies in STATA version 15.0. Missing data for all variables were verified and found to be less than 0.5%. Therefore, advanced missing data management procedures were not necessary and missing cases were excluded listwise(Tabachnick, Fidell, & Osterlind, 2001). Free-text comments from the two questions were merged and examined using a framework analysis approach (Ritchie & Lewis, 2003). This involved familiarization with the data, indexing, summarizing, synthesizing, and interpreting. Qualitative responses were analyzed by two researchers (EN and CF) with inter-rater reliability (IRR) of 0.85 (Ritchie & Spencer, 2002). Disagreements were resolved via discussion.

Results

The survey was distributed to 2721 PLWH, and data were available from $n = 653$ (24%) respondents out of 2721 PLWH were available for analysis as indicated in Table 1, most responses originated from patients utilizing services at the largest HIV service in Sussex (Brighton and Hove Lawson Unit: 75.5%) compared to smaller HIV services (24.5%).

Table 1. Socio-demographic characteristics of survey participants.

Characteristics	*n* (%)
Age	
20–39	93 (14.4)
40–59	381 (59.1)
>60	171 (26.5)
Gender	
Man, including trans man	522 (80.6)
Woman, including trans woman	117 (18.1)
Non-binary	8 (1.2)
Other	1 (0.1)
Ethnicity	
White (white British, Irish, or any other white background)	534 (82.8)
BAME (Asian/Asian British/Black/Black British/Mixed/Other Ethnic Groups)	109 (16.9)
Asian or Asian British	9 (1.4)
Black or Black British	83 (12.9)
Other ethnic groups	9 (1.4)
Mixed (White and Black, White and Asian or any other mixed background)	10 (1.5)
Sexual orientation	
Gay	451 (69.8)
Heterosexual/Straight	161 (24.9)
Bisexual	21 (3.3)
Other	4 (0.6)
Prefer not to say	9 (1.4)
Cohabitation arrangements	
Live with sexual partner	273 (42.3)
Live alone	209 (32.4)
Live in shared house or flat with friends and flatmates	75 (11.6)
Live with children	43 (6.7)
Live with relatives	40 (6.2)
Other	5 (0.8)
Homeless/insecurely housed/sofa surfing	1 (0.2)
HIV service centeres	
Brighton and Hove	
Lawson Unit	488 (75.5)
East Sussex	
Avenue House Clinic, Eastbourne	44 (6.8)
Station Plaza Clinic, Hastings	2 (0.3)
West Sussex	
Sexual Health, Chichester	36 (5.6)
Sexual Health, Crawley	40 (6.2)
Sexual Health, Worthing	36 (5.6)
Covid antigen testing	
No	562 (87.5)
Yes – tested negative	74 (11.5)
Yes – tested positive	6 (0.9%)
Covid antibody testing	
No	617 (95.5%)
Yes – tested negative	20 (3.1%)
Yes – tested positive	4 (0.6%)
Unsure	5 (0.8%)

Socio-demographic characteristics

Table 1 summarizes the socio-demographic characteristics of the sample. The age of respondents ranged from 20 to 85, with a mean age of 52.3 years (SD 11.3). Respondents who identified as male represented the majority of the sample (80.6%), reflective of the Sussex population of PLWH. 117 (18%) of respondents were women, and 109 (16.9%) were from Black African and other Minority Ethnic (BAME) backgrounds. Nearly a third of the respondents lived alone (32.4%). We did not collect information about the type of cART, adherence, or HIV viral load; however, in our setting is 98% of the cohort of PLWH is undetectable.

Changes in health during Covid-19

Less than a quarter (23%) of respondents reported a history of any Covid symptoms. Of those, 80 (13%) had a PCR test (6 positives), and 29 (5.5%) had an antibody test (4 positives). About 183 (28.3%) respondents considered that their physical health had worsened to some extent during the pandemic (Table 2). In terms of mental health, 501 (77.6%) respondents reported feeling more anxious than usual; 464 (71.8%) reported feeling more depressed than usual; 128 (19.8%) reported having suicidal thoughts; 472 (73.1%) reported having difficulties sleeping; and 161 (24.9%) reported excessive alcohol or drug use since the start of the pandemic.

Worsening mental health was a common theme identified throughout the qualitative analysis, with many of the responses indicating specific concerns around increased anxiety and depression: "My mental health has deteriorated quite dramatically. [The pandemic] has made me more anxious and hypersensitive". Perceptions of increased vulnerability to Covid-19 due to HIV also seemed to affect mental health:

> Just got very anxious. Could not sleep some nights. Only because could not find any information anywhere how would Covid-19 effect HIV (group) person.

> Scared of getting Covid-19 on top of HIV – I over protected myself.

In some cases, the Covid-19 pandemic triggered memories of the early days of HIV, as illustrated in the following quotes:

> Having had over 30 years since HIV/AIDS diagnosis – it has been an unpleasant feeling of De Ja Vu. Another deadly disease with very similar lockdown restrictions on life, social or sexual contact.

Table 2. Self-reported changes in physical and mental health among PLWH during the C19 pandemic.

Variable		*n* (%)
Poor health and wellbeing since the start of the Covid-19 pandemic	No	563 (86.9)
	Yes	85 (13.1)
Physical health has worsened since the start of the pandemic	No	464 (71.7)
	Yes	183 (28.3)
Display of symptoms of Covid-19 (fever and persistent cough, or loss of taste or smell) since the start of the pandemic	No	499 (77.1)
	Yes	148 (22.9)
Feeling more anxious or more worried than usual since the start of the pandemic	No	145 (22.5)
	Yes	501 (77.6)
Feeling depressed or low in mood more than usual since the start of the pandemic	No	182 (28.2)
	Yes	464 (71.8)
Suicidal thoughts since the start of the pandemic	No	520 (80.3)
	Yes	128 (19.8)
Difficulty sleeping since the start of the pandemic	No	174 (26.9)
	Yes	472 (73.1)
Excessive alcohol or drug consumption since the start of the pandemic	No	485 (75.1)
	Yes	161 (24.9)

[This pandemic] brings back memories of HIV in the 80s and early 90s, which can be challenging.

Accessibility of essential health services and information during Covid-19 pandemic

Many respondents worried about running out of their HIV medicine ($n = 264$, 40.7%); about accessing HIV services ($n = 246$, 38.0%) as well as other health services ($n = 408$, 63.0%); and about their sexual health ($n = 119$, 18.4%) during the pandemic (Table 3). Approximately half of the respondents ($n = 324$, 50.4%) felt that not enough support had been available for PLWH during the pandemic. Regarding access to medical treatment during the pandemic, 208 (32.2%) encountered difficulties while trying to access treatment, whereas 219 (33.9%) respondents avoided accessing services.

Regarding the accessibility of health information during the Covid-19 pandemic, 246 (38.3%) respondents accessed enough information on how Covid-19 may affect PLWH, and 193 (29.9%) received information on the support available for PLWH during the lockdown. Nearly two-thirds of respondents ($n = 468$, 72.2%) had concerns that HIV put them at heightened risk of Covid-related complications, which is also indicative of misinformation and confusion around HIV-Covid interactions. Some PLWH were unable to access information and support because of lack of access to technology ($n = 90$, 13.9%) and due to not knowing how to use the internet ($n = 75$, 11.6%). SMART phones were listed as the most helpful tool for accessing information and support during the pandemic ($n = 464$, 71.3%), and the main barrier to accessing information and support was a poor internet connection ($n = 40$, 6.1%). The most common mode of communication with the clinic was text messaging (60.7%), followed by phone calls (41.2%).

An evident theme of information provision also emerged in the qualitative analysis, with concerns around the lack and poor quality of the information provided: "No update on whether there is any evidence for harm in those who are HIV positive". In addition to this, there was also a clear theme around conflicting information received, which caused confusion and uncertainty among many respondents: "Received letter-to 'Shield' but found that not necessary. Had no brief verbally to do so […]. Should have been explained maybe – why? What for?"

Table 3. Accessibility of essential health services and information.

Variable		*n* (%)
Accessibility of health services		
Encountered problems accessing medical treatment, advice, or medicine during the pandemic	No	438 (67.8)
	Yes	208 (32.2)
Avoided accessing medical treatment, advice, or medicine during the pandemic	No	427 (66.1)
	Yes	219 (33.9)
Worried about running out of HIV medicine during the pandemic	No	384 (59.3)
	Yes	264 (40.7)
Worried about accessing HIV services during the pandemic	No	402 (62.0)
	Yes	246 (38.0)
Worried about accessing other health services during the pandemic	No	240 (37.0)
	Yes	408 (63.0)
Worried about sexual health and sexually transmitted infections during the pandemic	No	527 (81.6)
	Yes	119 (18.4)
Feels that enough support has been available for PLWH	No	324 (50.4)
	Yes	319 (49.6)
Accessibility of health information		
Accessed enough information on how Covid-19 affects PLWH	No	397 (61.7)
	Yes	246 (38.3)
Received information on the support available for PLWH during the lockdown	No	453 (70.1)
	Yes	193 (29.9)
Unable to access information and support for PLWH because of lack of access to technology during the pandemic	No	558 (86.1)
	Yes	90 (13.9)
Unable to access information and support for PLWH because of insufficient technological literacy during the pandemic	No	572 (88.4)
	Yes	75 (11.6)
Worried about HIV status increases the risk of Covid-related complications	No	180 (27.8)
	Yes	468 (72.2)
Technological resources and barriers		
Most helpful resources for accessing information and support during the pandemic	SMART phone	464 (71.3)
	Good internet connection/wi-fi	307 (47.2)
	Computer/PC/ Laptop	296 (45.5)
	TV, radio	225 (34.6)
	Tablet/iPad	200 (30.7)
	Video software	98 (15.1)
	Telephone	74 (11.4)
	None of these	32 (4.9)
Barriers to accessing information and support during the pandemic	Poor internet connection	40 (6.1)
	No computer access	21 (3.2)
	No video software	20 (3.1)
	No internet connection	13 (2.0)
	No telephone	9 (1.4)
	No SMART phone	8 (1.2)
	Internet illiteracy	6 (0.9)
	None of these	563 (86.5)
Main sources of information from health providers during the pandemic	Texts from clinic	395 (60.7)
	Phone call with clinic	268 (41.2)
	Emails from clinic	163 (25.0)
	EmERGE mobile app*	132 (20.3)
	Clinic website	47 (7.2)

[a]The EmERGE app is used in Brighton to facilitate linkage to services and provide PLWH with access to their results as part of a digital health pathway of care.

Socio-economic wellbeing of PLWH during the Covid-19 pandemic

With regard to disclosure concerns, 273 (42.1%) respondents reported being more worried than usual about people finding out about their HIV status, and 285 (44.0%) reported worries about data security issues since the start of the pandemic (Table 4). Moreover, 44 (6.8%) respondents reported having been discriminated against because of their HIV status, and 211 (32.6%) respondents reported worsening feelings of shame about their HIV status (internalized stigma) since the start of the pandemic. Qualitative data highlighted a nuanced relationship between Covid-19 and HIV stigma:

> For me it's just highlighted the stigma of having a disease especially when people obviously walk away from you to keep social distancing and whilst nothing to do with the HIV [it] just isn't a nice feeling but it's totally understandable

More than a third of respondents ($n = 235$, 36.3%) worried about safety in relationships since the start of the pandemic.

Widespread resilience was also noted: 537 (83.3%) of respondents felt that living with HIV had equipped them with the strength to adapt to the Covid-19 pandemic, and 623 (96.6%) felt able to cope with the situation. In terms of social support, 606 (93.5%) of respondents felt that they had enough support from people around them, and 231 (36.7%) found support from peers living with HIV helpful during the pandemic. Resilience also emerged as a theme in the qualitative analysis, suggesting that HIV may have helped many respondents to develop coping skills, which have been helpful during the Covid-19 pandemic. The following quotes illustrate this:

> At first I was worried but I now feel I have strength to get through this using my past experiences with HIV. I actually feel strong.

> As a long-term survivor I found it easier to adjust my behaviours to stop the spread of a virus. At the same time, it upsets me more when others are cavalier about protecting others by adjusting theirs (i.e. wearing masks, social distancing, etc.)

More than half of respondents (60.3%) had worried about money since the start of the pandemic, and 170 (26.2%) respondents reported being expected to work under unsafe conditions where there was a risk of contracting coronavirus. Employment concerns were also noted in the open-ended responses: "I have been furloughed, and will probably be made redundant, my real worry". Concerns were raised around confidentiality and forced disclosure of HIV status to employers: "At work when they were sending people to work from home, those who were at risk were first and prioritised of course. I found it hard to explain why I'm at risk without telling them I'm HIV".

Table 4. Socio-economic wellbeing of PLWH during Covid-19.

Variable		Total, *n* (%)
Stigma, discrimination, and safety concerns		
More worried than usual about people finding out about HIV status	No	375 (57.9)
	Yes	273 (42.1)
Treated unfairly because of HIV status since the start of the pandemic	No	604 (93.2)
	Yes	44 (6.8)
Worse feelings of shame about HIV status since the start of the pandemic	No	437 (67.4)
	Yes	211 (32.6)
Worried about data security issues since the start of the pandemic	No	363 (56.0)
	Yes	285 (44.0)
Worried about safety in relationships since the start of the pandemic	No	413 (63.7)
	Yes	235 (36.3)
Resilience and support		
Living with HIV has equipped me with the strength and personal resources to adapt to the Covid-19 pandemic	No	108 (16.7)
	Yes	537 (83.3)
Able to cope with the situation since the start of the pandemic	No	22 (3.4)
	Yes	623 (96.6)
Enough support from people around you since the start of the pandemic	No	42 (6.5)
	Yes	606 (93.5)
Community support from peers living with HIV was helpful during the Covid-19 pandemic	No	398 (63.3)
	Yes	231 (36.7)
Economic concerns		
Worried about money since the start of the pandemic	No	257 (39.7)
	Yes	391 (60.3)
Expected to work in unsafe conditions where there was a risk of contracting coronavirus	No	478 (73.8)
	Yes	170 (26.2)

Discussion

This study highlights important gaps between the needs of PLWH and the services that have been available to them during the Covid-19 pandemic. On the one hand, PLWH in our study reported on the multifaceted and growing needs to support their physical and mental health during the Covid-19 pandemic. At the same time, they reported difficulties accessing essential health services and information on how to take care of themselves during this pandemic. A number of social determinants of ill health were also noted: stigma and discrimination, safety concerns in relationships and at work, and financial insecurity. PLWH in this study also reported remarkable resilience, both at the individual level (emotional strength) and community level (peer support).

Our findings suggest that essential health information was poorly communicated with PLWH, often resulting in confusion and misinformation. As many as 40% of respondents worried about running out of their life-saving HIV medicines, which were never at risk of stock outs in Sussex. Half of the respondents felt that there had not been enough support for PLWH during the pandemic, which was further complicated by receiving conflicting information

on who needs to shield and why. UK Government advice on shielding finally focused only on PLWH, whose immune systems were severely compromised (CD4 < 350). However, in practice, the majority of PLWH with stable viral loads do not get their CD4 counts checked regularly (BHIVA HIV Monitoring Guidelines., 2019). This may have added to the uncertainty and confusion over the potential or increased risk of Covid-19 infection.

Open-ended qualitative data highlighted that the current pandemic triggered distressing memories for respondents who had lived through the AIDS pandemic of the 1980s and 1990s. Similar to Covid-19, the early days of the AIDS pandemic were characterized by fears of contagion, high morbidity and mortality, and profound changes in the practice of intimacy. Similarities between the two pandemics evoked psychological distress for PLWH. Prior to Covid-19, PLWH already experienced a disproportionate burden of depression (17–47%, versus 2–5% general population), anxiety (22–49%, versus 4–5% general population), and suicidality compared to their HIV-negative peers (Chaponda et al., 2018; Croxford et al., 2017). However, despite – or perhaps *because of* experiences with HIV – many PLWH displayed personal resilience and strength to cope with the pandemic.

Covid-19 prevention measures and public health messages are likely to have had inadvertent effects on perceived, anticipated, and internalized stigma among PLWH. Respondents commonly reported worries about people finding out about their HIV status (42.1%), as well as worries about data security issues (44.0%) since the start of the pandemic. The reasons for this are unknown. Covid-19 testing and tracing mechanisms might evoke worries about data confidentiality. Shielding advice for PLWH may have inadvertently increased worries about HIV disclosure, as PLWH felt the need to explain to employers and colleagues their reasons for shielding. Interestingly, only 6.8% of respondents reported having been discriminated against due to HIV, but as many as 32.6% of respondents reported worsening feelings of HIV-related shame since the start of the pandemic, suggesting an increase in internalized stigma. Although the social distancing measures had nothing to do with HIV, they were reminiscent of HIV-related stigma. This might explain the difference in relatively low levels of reported discrimination compared to the high prevalence of HIV-related shame.

Limitations

The survey was conducted in a cohort of PLWH consisting mainly of men who have sex with men of white ethnicity, which is not representative of the wider population of PLWH in the UK. However, the large sample size resulted in 117 (18%) responses from women and 109 (16.9%) responses from PLWH with Black African and other Minority Ethnic (BAME) backgrounds. There is also a significant reporting bias associated with the online-based nature of the survey, as only those with access to the internet were able to participate. This is likely to have resulted in an underestimate of the percentage of PLWH with difficulties using technology and remote health services. In particular, the impact of Covid-19 on many of the most vulnerable might not be proportionately reflected in the survey's findings.

Our findings highlight an urgent need for action, particularly in four critical areas: (a) *Health communication strategy*: There is an urgent need for a clear strategy both nationally and locally for the dissemination of unambiguous information for PLWH. This is essential both for the current Covid-19 pandemic and for future epidemics. The communication strategy should be informed by input from PLWH and the community sector. Recent work from BHIVA demonstrates that this is feasible (BHIVA., 2020a; BHIVA., 2020b). Communication strategies should be sensitive to this reality and avoid messaging that could evoke worries around stigma and discrimination. (b) *Meaningful community engagement*: All services and support for PLWH should be grounded in the Greater Involvement of People Living with HIV/AIDS (GIPA) Principles. We found clear evidence of ambiguity in essential health communication for PLWH, which is likely to have been avoided had PLWH been involved in the drafting of this communication. (c) *Mental health services*: Our findings suggest that the pandemic has further exacerbated mental health difficulties among PLWH. There is an urgent need for increased mental health provision for PLWH. A further understanding of resilience among PLWH will assist in developing targeted interventions using a community wealth centered approach. (d) *Socio-economic support*: Economic insecurity and unsafe working conditions were major concerns for our participants. Currently, clinical HIV services take this into account as part of holistic assessments, but they are not funded to provide relevant support for these specific issues.

This study highlight important gaps between the multifaceted needs of PLWH and the limited services available to them. Multisectoral collaborations and investments are urgently needed to adequately support PLWH and to further build and sustain resilience to future shocks within HIV services.

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JHV and MP designed and conceptualized this study. JW, EN, CF, KM, MT, MD contributed to the study

idea and data analysis. WS and MJ contributed to data collection. MP, KM, and JHV drafted the manuscript. All authors revised the manuscript.

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